

*Next Meeting – Monday, August 6, 2007 – 2 PM
Appoquinimink State Service Center
Middletown, Delaware*

**STATE COUNCIL FOR PERSONS WITH DISABILITIES
BRAIN INJURY COMMITTEE
May 7, 2007 – 2:00 PM
APPOQUINIMINK STATE SERVICE CENTER
MIDDLETOWN, DELAWARE**

PRESENT: John Goodier, Chair; Brian Hartman, Co-Chair; Ray Brouillette, Easter Seals; Dr. Jane Crowley, A.I. DuPont Hospital; Laura Cygan, DPH; Adam Fisher, DOE; Linda Heller, DSAAPD; Lora Lewis, DPH; Chris Long, DDDS; Dr. Bradley Meier, DPC; Tom Parvis, DVR; Ann Phillips, Parent; Al Rose, DDC; Liz Schantz, Consumer; Kyle Hodges, Staff and Linda Bates, Support Staff

ABSENT: Jim Burcham, BIAD; Dr. Jackie Christman, DPH; Virginia Corrigan, Christiana Care; Aaron Deede, Consumer; Ellen deVrind, Christiana Counseling; Tony Horstman, SCPD; Dr. Dan Keating, Bancroft Neurohealth; Janet Leitch, Consumer; Mike Merrill, VR/U.S. DVA; Beth Mineo Mollica, DATI; Dawn Stewart, Healthy Living; and Wendy Strauss, GACEC

GUESTS:

Dan Madrid, DVR Counselor
Gina Perez, Advances in Management
Jim Salt, UD/CDS;

CALL TO ORDER

The meeting was called to order at 2:00 PM.

APPROVAL OF MINUTES

Motion was made, seconded and approved to accept the February 5, 2007 meeting minutes as submitted.

AGENDA ADDITIONS/DELETIONS

- Jane Crowley will address the TBI registry.

BUSINESS

TBI Grant Update

Lora Lewis from the Division of Public Health gave the following update on her hand-out—

- The TBI Grant has been approved for year two.
- Six MOUs and/or contracts are in the works [e.g. BIAD; SCPD for \$9,000 (training/education)]
- A facilitator has been confirmed for issues regarding a waiver for children; sustainability and registry/surveillance issues.
- Lora is in the process of finding an evaluator for the Year 2 evaluation piece.
- Regarding the Family Ambassador program at the AI DuPont hospital/Dr. Jane Crowley, the contract is in the process of being signed. In this contract, Jane will solicit participation of family members to be trained and Jane will design a program for their participation. Jane's concentration will be education in the schools.
- The Coordinating Council for Children with Disabilities (CCCD) is another contract. Lora is waiting for them to produce some more data before she gives them any more money.
- Lora will send a copy of the budget description to Kyle.

Year 1 Grant Evaluation

Gina Perez with Advances in Management passed out an Evaluation Summary regarding the *TBI Implementation Grant Program Evaluation Report*. This outline is an example of how Years Two and Three could be enhanced as a result of what happened in Year One. A complete copy of the TBI Implementation Grant Program Evaluation Report was also provided.

A little background on what the **Grant Requirements** were for Year One—

TBI Awareness

Target Audiences:

Providers & Consumers

Activities:

Website

Public Service Announcements

Materials Dissemination

➤ General Information

➤ Resource Directory

Needs Assessment/Gap Analysis—the Center for Disabilities Studies (CDS) conducted a survey:

- Identify existing services
- Determine where there are gaps in services

- Identify workforce training needs

TBI Incidence and Prevalence Analysis—CDS also examined this in its report

- Determine the degree to which incidence and prevalence data is available for TBI
- Evaluate the gaps in data
- Provide guidance for addressing the need for accurate TBI data in the future.

Policy Development—Brain Injury Committee:

- Identify components of an effective and comprehensive TBI system
- Identify policy and regulatory barriers
- Develop plans for changing legislation
- Regulations and policies which compromise TBI services
- Identify appropriate individuals and organizations to promote change to the policy, regulations or legislation.

Methodology

- Reviewed contracts
- Reviewed grant
- Conducted interviews
- Reviewed meeting minutes (BIC)
- Reviewed reports – BIAD; Public Health Injury Prevention; Center for Disabilities Studies
- Navigated the website—Gina looked for TBI information as if she was looking for information for herself or a family member; and looked at other brain injury websites to get some ideas.
- Reviewed materials

Findings and Recommendations:

TBI Awareness

Website is a good foundation

- Make updates and changes to improve navigation and quality of information—Gina felt that the website was hard to navigate and that the information was on too high of a reading level since the average reading level is 6th grade.

Public Service Announcements (PSAs) should be a broader awareness campaign

- Conduct strategic planning—what is the message that the TBI community wants to send to the general public?
- Develop a prevention and education message for TBI

- Leverage resources—Gina suggested working with other organizations and trying to leverage over resources and looking at fundraising opportunities. Once you have a message, it is a lot easier to get others excited about giving money, e.g. corporations.

John asked if Gina was keeping in mind that the money from this contract pays for an office and two part-time people who are now doing the work that three volunteers had done. Gina replied absolutely, it is all in that context.

Kyle and Brian asked if this report is a draft or final. Lora replied that at this point, she has not gotten a clear answer from the Feds and she will let us know as soon as possible.

Chris asked if we wanted to add important issues, could that be an addendum? Lora replied that these issues could accompany the report; not be included in the report. Therefore, please forward any feedback/comments to Kyle. Lora said she does not have a due date. Chris added that it should be decided today when to get any comments to Kyle and then to Lora; and also that this will not be submitted to the Feds until we do this. Lora suggested that when you look at this evaluation, look at it in the context of how we could do things better. The report gives concrete suggestions of how to make things better. Chris wants to see that we get credit where credit is due. Lora stated that Gina is documenting information that is available to the public, via the Internet, or in writing. Lora added that the information may be there, but it needs to be made apparent. Kyle added that the full report needs to be read and to look at the suggestions. If there is anything that may be missing that might have a determination on the results and evaluation, that is something that we would want to provide. Gina added that her comments are meant to be constructive, and there is a lot of information which has been done with minimal funding; however, Gina is pointing out some bigger issues and it is a fair assessment of the positives and what may need improvement.

BIAD Welcome Packet is comprehensive

- Materials should be made more readable/understandable
- Information should be more widely disseminated

Resource Directory is a good start

- Target audience should be reassessed
- Consider format changes that make it more user friendly
- Make the information more understandable
- Reconsider content and/or audience

Gina added that a little more time should be spent on the format of the Resource Directory. Gina felt that it was difficult to navigate through this information if she were putting on the hat of a family member trying to access information on TBI.

The target population is very broad. BIAD may want to consider providing very complex medical information for providers and then general website or contact information targeted more towards the community or a person with TBI. You may want to consider separate resource directories by the populations.

Needs Assessment/Gap Analysis

Comprehensive survey list

- Overlap among respondents should be discussed. Gina added that this could skew the results.

Data is reported but not analyzed

- Data analysis should support study findings/recommendations

Survey instrument was confusing and could lead to skewed results

- Relationship to 1998 study should be addressed
- Consider changes to survey instrument if repeated

Confidentiality hinders usefulness of data

- Training needs should be further evaluated—Gina added that not being able to know who is providing these services is a challenge.
- Respondents should be contacted for permission to identify them

Increase TBI Professionals' knowledge about services and best practices

- Based on needs assessment:
 - Further explore current training—go back to organizations to ask for the information to be revealed
 - Define training needs of those surveyed
 - Collaborative with professional associations—work with medical, nursing, social work society to establish training programs and provide continuing education
 - Evaluate training programs

TBI Incidence and Prevalence Analysis--this was done by the Center for Disabilities Studies

Survey methodology is unclear

- Provide survey instrument
- Define data collection process
- Discuss relationship to 1998 survey—no reference to this data

Good overview of the organizations who collect data

- Data collection tools and data sets should be detailed
- Explore other data sources that may be available
 - Safety and Homeland Security
 - Criminal Justice Information System
 - Hospital services not provided through the ER
- Develop a workgroup to determine common data elements and gaps in data
- Look for opportunities to enhance current data collection/reporting

Data is reported but not analyzed

- Provide an analysis of the incidence and prevalence of TBI
- Quantify the change in TBI incidence and prevalence from 1998 study

Policy Development

Objective Met

- The BIC has done a great deal to affect change in public policy to support TBI system of care
 - Continue Medicaid waiver activities
 - Identify opportunities to include children

Recommendations for Future Grant Years

Conduct strategic planning

- Tie study findings to plan for improving system of care—the BIC and the BIAD need to tie in their priorities.

Kyle added that the BIC needs to get involved with the TBI registry.

Lora asked what we are going to do for children since there is not a Medicaid waiver for children or adults. Lora said that if these things can be accomplished without a facilitator, then we can use the facilitator for something else.

Evaluate effectiveness of awareness activities

- Implement pre- and post- test—Gina added that a baseline for awareness in the state could not be established for TBI. Kyle added that something similar to a pre and post was done at the TBI Conference in April. Gina also said to add a comment form for the website.

Explore opportunities to legislate/regulate reporting of TBI incidence to the Trauma Registry

Kyle added that this will be a very big undertaking as there will be funding involved.

Develop funding strategies for:

- TBI awareness
- Provider training
- Development/enhancement of a TBI registry
- Providing direct services in areas of need

Brian suggested that we make a timeline for comments back to Kyle from the BIC. Jim added that in the future it would be good to have a copy of the draft report earlier to be able to comment and process the document. Kyle said he did request a draft copy via e-mail on behalf of the BIC of this report prior to the meeting. Lora added that we do not have to decide by the end of the grant year what the registry is going to look like or who is going to own it—we have to be moving along in the process. Kyle said that for the future, what is the division's perspective on providing draft reports since he did request draft copies of the CDS report and Gina's evaluation report? Lora replied that she did not want the agencies being evaluated in this report coming to this meeting with a laundry list of things that they did not agree with. Lora wanted the report to be looked at in a positive way. It was Lora's decision to not share the report. Chris added that since the BIC is an advisory group, we should have the opportunity to evaluate and ask questions and be involved in the process. Lora stated that is not the BIC's assessment; it is Gina's and the University of Delaware. Lora added that the addendum from the BIC can be added. Brian added that if we would have had this draft report in advance, we could have had more meaningful discussions; and we could pick out things that are obviously in error and present that. Lora said that she is hearing and listening to the Committee's comments. Jim Salt said that the process that they are used to is very collaborative, very sharing in the draft stages with a much more open discussion. Jim added that they felt a little hand-cuffed at the CDS that they could not share with the BIC. It would have been great to have a conversation with Gina as she was looking at the report and had questions. Lora reported that she said that the report could be shared after CDS looked at the comments. It was agreed that planning ahead now for this stage next year is helpful.

PATI Report

I. DDDS Eligibility Regulation

In 2002-2003 the SCPD Brain Injury Committee provided input on proposed revisions to DDDS eligibility standards. In 2003, the Division deferred further action on the regulation. It has now resurrected the initiative. Brian attached the current regulation, the proposed regulation, and his April 25 critique which was endorsed by the GACEC and SCPD. On April 26 Brian, Kyle, Wendy Strauss and Pat Maichle participated in a meeting with DDDS to provide further input.

As Brian's April 25 critique indicates, the proposed regulation deletes the current

reference to brain injury. This could obviously have a major impact on access to DDDS services by persons with TBI. The DLP will continue to advocate for a more inclusive DDDS eligibility regulation.

Brian added that they would like DDDS to reinsert “brain injury”. They agreed to adopt a cut-off age of 22. DDDS will consider our recommendations and hopefully they will give us another draft—if not it will have to go through the register of regulations.

II. Abuse/Neglect Investigation Lawsuit

Consistent with an April 28 News Journal article, the DLP has filed suit in federal court to compel a mental health provider to cooperate with an abuse/neglect investigation. The provider was responsible for providing case management and support services to an individual with mental illness residing in NAMI housing. Under federal law, the DLP is entitled access to records of persons with mental illness if it has either received a complaint or has probable cause to believe that abuse or neglect has occurred. In this case, the individual was ostensibly dead for days before being discovered.

Although the deceased individual was not a brain injury survivor, the lawsuit would affect the scope of the DLP’s authority to investigate abuse/neglect of individuals with TBI. The DLP seeks an injunction compelling the provider to supply access to relevant records.

Brian will keep us updated.

III. New Castle County Accessory Dwelling Unit Ordinance

Consistent with an April 11, 2007 News Journal article, New Castle County recently adopted an ordinance authorizing accessory dwelling units (ADUs). The SCPD, DLP, and GACEC facilitated passage. DLP and SCPD representatives provided supportive testimony in a hearing on the legislation. The DLP provided technical assistance to the Council to diminish opposition. A substitute bill was introduced which incorporated two DLP options, i.e. establishing a cap on the number of authorized ADUs and requiring a deed restriction to enhance enforcement of limitations. The ordinance “squeaked” through the Council by a 7-6 vote.

ADUs have great potential for providing supportive housing to persons with TBI. A family could build an addition on a home with separate living and cooking quarters for a TBI survivor. The survivor would enjoy his/her “own space” while family support remains nearby. Since the survivor resides in a distinct dwelling unit, the survivor can qualify for public assistance programs (e.g. Food Stamps) without counting the income/resources of persons residing in the main dwelling.

IV. New Castle County “Family” Zoning Ordinance

Consistent with an April 25 News Journal article, ordinance, and email, New Castle County is proposing to reduce the number of unrelated individuals who constitute a “family” for purposes of single family zoning. Under current law, up to four (4) unrelated individuals can live together in a single family zoning district. The proposed ordinance would reduce this authorization to three (3) unrelated individuals.

The ordinance could have a significant effect on housing for persons with disabilities. Although there is a state zoning exemption statute for group homes for persons with disabilities, the exemption only covers 24-hour staffed residences. If an agency (e.g. ARC; NAMI; BIA) wished to sponsor a small congregate living arrangement of four (4) individuals living in a home with intermittent supports, this would violate the new ordinance.

The SCPD and other organizations oppose this initiative. Other organizations are encouraged to do likewise. If it appears that the ordinance is likely to pass, an amendment exempting persons with disabilities may be a promising option.

Brian said that we may have to send a letter to amend this ordinance to not apply to people with disabilities.

V. Heroes at Home Act of 2007 (S.1065)

Senator Clinton introduced this bill on March 29, 2007. It is designed to improve services and supports for Armed Services personnel with TBI and their families. The Brain Injury Association of America highlights the following two significant benefits of the bill:

Implementation of an objective, computer-based assessment protocol to measure cognitive functioning both prior to and after deployment in order to improve the screening process for TBI in soldiers deployed to Iraq and Afghanistan

Establishment of a Traumatic Brain Injury Family Caregiver Personal Care Attendant Training and Certification Program, which would train and certify family caregivers of TBI patients as personal care attendants, enabling them to provide quality care at home while also qualifying for compensation from the VA

The bill has six (6) co-sponsors. The BIAA is encouraging constituents to solicit other Senators to sign up as co-sponsors. A sample letter is attached.

The SCPD, and other organizations, may wish to contact Senators Carper and Biden to provide perspective on the importance of this legislation.

Motion was made, seconded and approved for the SCPD to write a letter to Senators Biden and Carper to co-sponsor the “Heroes at Home Act of 2007”.

VI. H.B. No. 78 (Ban on Hand-held Cell Phone Use in Vehicles)

The SCPD and GACEC recently endorsed Brian's analysis of legislation designed to ban hand-held cell phone use in vehicles. An article recites that 188 accidents in Delaware in 2006 involved cell-phone use. Since this is a TBI-prevention bill, other organizations may also wish to consider endorsement.

Kyle noted that as of today, the bill was left on the table.

VII. S.B. No. 46 (Motorcycle Helmet Bill)

The SCPD and GACEC recently endorsed Brian's analysis of legislation which would require all operators and passengers on motorcycles to wear a helmet. This is important TBI-prevention legislation. Other organizations may also wish to endorse the bill.

VIII. Motorcycle Safety Campaign

May is national motorcycle safety month. In observance of this designation, the Delaware Office of Highway Safety has initiated a campaign to foster motorcycle safety among motorcyclists and other drivers. The article indicates that 21 persons died in motorcycle crashes in 2005. In 2006, fatalities were reduced to 12 persons with an average age of 25.

IX. "Highway Safety Saturday" Project

The Delaware State Police recently conducted a series of seminars on driving safety. The State Police stressed the need to wear seatbelts and also targeted inattentive driving. The News Release notes that both the number of crashes and driving fatalities in Delaware is on the rise.

X. Delaware Teen Driver Accident Statistics

The SCPD routinely comments on legislation affecting teen drivers. The importance of such legislation is underscored in an article from the Delaware BIA's Winter/Spring 2007 newsletter. As the article indicates, the National Safety Council ranks Delaware 4th in the Nation in teen driving fatalities. Rankings for neighboring states were much better - Pennsylvania -23; Maryland - 35; and New Jersey - 49. The ranking is based on the percent of young drivers involved in fatal crashes adjusted by each state's 16-20 year old driving population.

The article summarizes research involving teen judgment and risk taking behavior:

Researchers are finding that the area of the brain that governs weighing consequences of one's actions, suppressing impulses and organizing thoughts does not fully mature until about age 25. In addition, hormones are active and influencing the brain's neurochemicals that regulate excitability and mood.

Obviously, the Council should continue to consider legislation affecting teen driver safety as important initiatives. Apart from fatalities, teen accidents often result in TBI. Parenthetically, the research findings on teen judgment could also be cited in support of the Council's bike/motorized scooter bill.

XI. Brain Injury Conference

Brian provided materials regarding a brain injury conference which is being convened in June in Williamsburg, Virginia. The conference include sessions on problems with identification of students with TBI in special education, meeting the challenges of veterans with TBI, concussive brain injury, employment of persons with TBI, and pediatric interventions for children with TBI.

DSAAPD/DMMA Waivers

Brian gave the following overview—

Kyle, John, Brian and Scott Ponamen, their consultant, met with the new administration within DSAAPD on May 2 to talk about the ABI waiver situation.

By way of background, a couple of year's ago, we worked with the division and they got an ABI Medicaid waiver approved by the federal government, CMS. There was difficulty implementing it because of a lack of sufficient providers. DSAAPD decided, to the BICs surprise, to pull that waiver. Subsequently, the plan was to amend two of our existing Medicaid waivers to include some target services for people with TBI and to use medical necessity as a way to limit eligibility getting those services. DSAAPD thought that they could get this approved by CMS. There was a conference call in March with CMS—Brian has a copy of the presentation. CMS then had an administration change in the regional office. The new CMS administration did not like the latest approach because they felt that it was a waiver within a waiver which they like to discourage. So, CMS is encouraging the state to go back to the original proposal, a discreet ABI waiver. So, that is what DSAAPD is working on at this time. DHSS' Secretary Meconi has committed resources to this waiver. They envision this to be implemented by December 2007. The Secretary has ensured the match funding of about \$350,000-\$400,000 which is not full year funded. Brian asked about input on the draft from the BIC; however, DSAAPD will be giving us only status reports instead at this point. Brian noted that currently, the division's intention is to have the eligibility standard for ABI waiver services be age 18 or older. This is inconsistent with other practices; so they agreed to revisit that issue. Brian said that they stressed the importance of working in concert with Public Health on the implementation grant since we are the advisory committee to this grant. Since Lora is in the same department, they will be giving her status reports. DSAAPD said that they are not going to count towards the cap what you are getting through the state programs; but it would help if they were talking to the other divisions. Brian feels that it would help if DDDS and Public Health would make contact and say that they would like to provide input. Linda feels that input from the various agencies would helpful in the process to

make sure their concerns are addressed. Brian noted that the cap will be 50 persons in the first year.

Peachtree Acres Presentation

Kyle noted that he had received a phone call from a person who has a son at Peachtree. The person stated that the services are not that good. He also stated that his son does not get a lot of therapy; a lot of people are overweight; and there is a lack of social activities. Many of the workers are not trained in brain injury and there are people there who do not have a brain injury or spinal injury which is the target population for this group. Also, his son was going to be asked to leave Peach Tree several times because they cannot provide services; so, he contacted Rep. Oberle and that issue has been resolved. John noted that with the change of management, things have been improved.

Kyle suggested having a presentation from Howard Hitch, the Board Chair and Christine Malaney, the Peachtree Manager. It was also suggested that we could visit Peachtree. Kyle will contact Howard Hitch and Christine. Devon noted that they are very receptive to visits.

Transition Assistance Program for Veterans

Mike Merrill is not here today; however, Kyle stated the following:

Mike had spoken about a Transition Assistance Program (TAP) for Veterans to review all the VA benefits and many other transition subjects for Veterans that are coming back from Iraq. Mike had invited us to take a tour of the DAFB to see what the Veteran's Administration does for providing services for veterans. Brian suggested that we have volunteer representatives from the Committee attend. Kyle will send out a few good dates to all via e-mail.

April TBI Training

Kyle announced that the April 17 training directed towards the Department of Education (DOE) along with school nurses, nursing students, etc. had an attendance of 100 persons. A lot of help was received by Wendy and DOE. Most of the thanks go to Dr. Jane Crowley, who coordinated, facilitated, presented, and moderated and was able to influence AI DuPont staff to conduct sessions and provide support... It was a very successful conference. We received 80 responses; and the conference received a 3.5 out of 4 on the question of "the degree to which you achieved your personal objectives".

Jane also thanked everyone and noted that there was good representation from school psychologists, special education directors, etc. from all the Delaware counties.

OTHER BUSINESS

TBI Registry

Jane encouraged the BIC to address the development of a TBI Registry. The second thing is the funding source for the Registry that is outside allocations of the state's general budget and the federal grant program. New Jersey receives additional funding through a motor vehicle surcharge. Jane would like to know if there is a way to resolve and address these issues.

Kyle said regarding the registry, one of the consultants that Lora will be hiring will be helping us with this issue. Kyle said that we may need to obtain better data on numbers of individuals with TBI before we examine the feasibility of funding from surcharges.

Jane replied that the Registry could just provide data on incidences of TBI. The hospital discharge data only captures those who are admitted. John said in the BIADs 1,600 mailings per month, Margie would know who are survivors and who are caregivers. Jane reported that this would be a good preliminary number by population. Devon said that going forward, we may need to address ER admittance records or other facility records. Jane said yes; and it takes money and devoted people at each site as there are eight emergency rooms in Delaware. However, people also go to their family doctors, malls and private clinics which do not make it to the registry. Kyle noted that the point is to have formalized and standardized data. Lora asked how the BIC wants to move forward with the consultant's role. Brian added that he would like the Public Health people in charge of the registry present to us how it works. Brian said the most likely way to achieve this is to add on to the existing infrastructure. Lora added that there are two persons – Mary Sue Jones and Douglas Rich that work on two registries and Lora will contact them to attend the next meeting. Lora will let Kyle know if they can attend.

ANNOUNCEMENTS

- John announced that Jim Burcham, BIADs Executive Director, passed the Certified Brain Injury Specialist (CBIS) examination and now he is the only specialist in the State of Delaware. Francina Rhoades was dismissed as the administrative assistant on April 5. A replacement will be on board as of June 1.

ADJOURNMENT

The meeting was adjourned at 4:22 PM.

Respectively submitted,

Kyle Hodges
SCPD Administrator

